The Auditor State of Hawaii

OVERVIEW

Study of Proposed Mandatory Health Insurance Coverage for Medical Foods in the Treatment of Inherited Metabolic Diseases

Report No. 99-4, January 1999

Summary

Senate Concurrent Resolution No. 19, Senate Draft 1, House Draft 1 of the 1998 legislative session requested the State Auditor to study the social and financial impacts of requiring all employer group health policies, contracts, plans, or agreements issued on a group or individual basis to provide coverage for foods that are medically necessary for the treatment of inherited metabolic diseases. Coverage, according to the proposed legislation (S.B. No. 2408, S.D. 1), is to be provided for at least 80 percent of the cost of care. We conducted our review pursuant to the social and financial impact criteria set forth under Section 23-52, Hawaii Revised Statutes.

Inherited metabolic diseases are disorders caused by abnormalities resulting from the inability of the body to metabolize or process certain nutrients. Without early diagnosis and treatment, metabolic disorders can result in irreversible mental retardation, severe health complications, and in some cases death. Metabolic diseases can be detected through screening programs. Currently, the Department of Health through its Hawaii Newborn Screening Program screens for seven disorders, including inherited metabolic diseases. While treatment is variable, a restricted and monitored diet consisting of "medical foods" or special formulas, modified solid foods such as low-protein foods, and portions of regular foods, is an established standard of care for some types of inherited metabolic diseases.

S.B. No. 2408, S.D. 1 of the 1998 legislative session would require private insurers governed under Articles 431:10A (commercial insurers) and 432:1 (mutual benefit societies such as HMSA) and Chapter 432D (health maintenance organizations) to provide coverage for 80 percent of the cost of medical foods provided that they are: (1) prescribed as medically necessary for the therapeutic treatment of inherited metabolic diseases and (2) administered under the supervision of a licensed physician. Currently, at least 21 states mandate some type of insurance coverage for medical foods to treat inherited metabolic diseases.

As of December 1998 the Department of Health identified 22 individuals in Hawaii that require medical foods for treatment. The department reports that 17 of 22 are provided insurance coverage, either through public or private health plans, for special formulas, but not for modified solid foods. Five individuals currently have no insurance coverage.

Lack or inadequate insurance coverage does not generally result in individuals not being able to obtain necessary treatment since lack of treatment has dire consequences. However, the lack of insurance coverage can result in unreasonable

financial hardships on those needing services. Families without insurance coverage for treatment can incur annual out-of-pocket expenses in excess of \$10,000 for medical foods. Demand for medical foods treatment and for insurance coverage comes from individuals and their families in need of medical foods and from health professionals and provider organizations. We found no indication that employer groups and unions are interested in these services or would demand coverage for them.

Financial impact caused by passage of this legislation should be minimal since so few individuals in the State require this form of treatment. However, we found organizations and insurers oppose coverage even though the financial impact for coverage is expected to be minimal. Additionally, passage of this proposed legislation may not benefit all individuals currently lacking coverage. This legislation affects only some private insurers, mutual benefit societies, and health maintenance organizations. The legislation would not affect individuals receiving coverage under public health plans and these private health plans not governed under the statutes that would be amended by the proposed legislation.

Recommendations and Response

We made no formal recommendations. The Department of Health provided us with a few technical and editorial suggestions for purposes of clarification which were incorporated in the study. The department also noted that it had been informed that changes to clarify the type of food products to be covered were being prepared for the proposed legislation.